

**COORDINATING SYSTEMS SERVING CARERS OF
CHILDREN AND ADULTS WITH DEVELOPMENTAL
DISABILITIES**

Matthew P. Janicki, Ph.D.

Director for Technical Assistance

RRTC on Aging with Developmental Disabilities

University of Illinois at Chicago

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EXECUTIVE SUMMARY

With the recent passage of the Older American Act amendments of 2000 and the initiation of the National Family Caregiver Support Program, the Administration on Aging and its constituent parts *formally* recognized their role in providing care and supports for carers of children and older adults with intellectual and developmental disabilities. *Developmental disabilities* refers to a group of conditions or disabilities that occur prior to or at birth, or during childhood, and interfere with normal growth and development. People with such disabilities may have difficulty being fully independent in work, housing, and social situations, which may continue into old age. Informed projections of the number of children and adults living at home with their parents or other carers are difficult to make, but it is estimated that some 1.9 million persons with developmental disabilities live with an informal carer. Approximately 25 percent of these carers are age 60 and older. For many years, state developmental disabilities' agencies targeted support services toward younger age parents, while support services for *older* carers were virtually nonexistent. However, current belief is that most people with an intellectual disability will have a life expectancy typical of other people. In addition, recent generations of older people are remaining healthier and less impaired longer than past generations, which is resulting in the number of older carers growing larger each year. As a result, support services are increasingly being targeted toward these older carers.

Many of these families providing at home support for people with a developmental disability have the same needs as other families in caring situations, but the main difference is that these "perpetual parents" are lifelong caregivers. As they age, they want: (1) services that meet their immediate needs (such as respite, housekeeping assistance, transportation, and emotional supports); (2) help with getting financial supports or determinations of eligibility; (3) help with obtaining financial planning information (such as, information on entitlements, guardianship and trusts); (4) help with negotiating the service system and advocacy for obtaining services for which they are eligible; (5) assistance with obtaining Medicaid and resolving problems with social services agencies; and (6) help with making decisions about their lives or the lives of the person for whom they are caring. Many such older carers are mothers and have provided care throughout the life of their adult son or daughter. Other relative carers include grandmothers, aunts, wives, sisters and cousins. Fathers, husbands, brothers and nephews are also primary carers, but to a lesser extent.

Aging adults with intellectual and developmental disabilities face many of the same challenges as other aging adults. They experience physical aging, social isolation, disengagement from work or activities, and the challenges of retirement. Yet, they differ because they may: have had limited social and vocational experiences; face the loss of their family home (with the infirmity or death of their parents or carers) and need alternative housing (sometimes precipitously); need help with medical and social resources; and need help accessing senior services or specialty developmental disabilities services.

In undertaking an initiative to serve older carers of individuals with a developmental disability under the NFCSP, it is helpful to first determine the number and nature of such families in the catchment area. In addition, the following questions should be investigated: (1) what are their needs and which are most immediate? (2) what resources currently exist in your community to help these families? (3) what are the disability and social services networks doing to help such families and carers? and (4) how can the Area Agency on Aging interface with existing efforts, or spearhead

the initiation of a new effort? Another decision point is whether to undertake this type of initiative within the aging agency or contract it out. This decision may be governed by whether the aging agency does direct work, normally contracts out, or works through other agencies. Once the decision is made to undertake a specialized initiative under the NFCSP, community development or coordination activities should be undertaken including: networking with the disability community, developing community coalitions, setting up interagency agreements, and making sure that the family services providers know about the initiative and how it will work.

Working within the greater disability system to build the NFCSP initiative can be more productive than attempting to do it in isolation for several reasons: (1) drawing in the disability providers will provide for a valuable set of resources that can be called upon when the family or an individual within the family needs assistance; (2) sharing of scarce financial resources can help stretch the available funds under the NFCSP so as to optimize outreach and assistance efforts; (3) many of the families that are found or contacted may already be in touch with other networks and collaboration will negate duplication of effort or waste of scarce resources; and (4) institutionalizing help for older carers within the community's planning and resource allocations structure will call for cooperation and collaboration.

INTRODUCTION

The U.S. Administration on Aging has long recognized that older families and others who care for a relative with a developmental disability are in need of special supports. These families may need special attention because, unlike other carers who have recently begun looking after an older relative, they have been providing lifelong care and their own aging may result in an increasing need for special supports. With the recent passage of the Older American Act amendments of 2000 and the initiation of the National Family Caregiver Support Program, the Administration on Aging and its constituent parts *formally* recognized their role in providing supports for this group of carers. This came about because the legislative language specifically calls upon priority to be given to “older individuals providing care and support to persons with mental retardation and related developmental disabilities.” Such individuals may include parents and other carers, such as other relatives, grandparents, friends, neighbors, and anyone else who may need support so that he or she may continue to provide primary care.

The Challenge

How can area agencies on aging respond to the mandates of the National Family Caregiver Support Act and set up outreach, enhance their information and referral, and provide casework and general assistance to families caring for someone with a developmental disability and, when appropriate, link these families to the local developmental disabilities providers?

WHAT IS A DEVELOPMENTAL DISABILITY?

The Older Americans Act specifically refers to carers of people with developmental disabilities as a priority population. The term “developmental disabilities” is used as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001). *Developmental disabilities* refers to a group of conditions or disabilities that occur prior to or at birth, or during childhood, and interfere with normal growth and development. The conditions may impede lifelong learning, intellect, and/or physical capabilities. People with such disabilities may have difficulty being fully independent in work, housing and social settings, which may continue through old age (Janicki 1991; 1993).

Generally, to be classified as a *developmental disability*, a condition must interfere with functioning in several life activity areas, such as caring for oneself, making life decisions, and earning an income (this is the “functional” aspect of the definition). In many states, a “categorical” approach to the definition is also used. Categorical (or diagnostic) conditions such as “mental retardation,” autism, cerebral palsy, epilepsy, and sensory or neurological impairments may qualify as a developmental disability. Contemporary practice is not to use “mental retardation” with reference to people with limited intellectual skills because it has acquired pejorative connotations; the preferred term is “intellectual disability” and is used in this paper in lieu of “mental retardation.” It is important to note that intellectual disabilities are one of a number of developmental disabilities and the two terms are not synonymous.

Regardless of whether a functional or categorical approach is used, according to federal statute the impairment associated with a developmental disability must have first occurred prior to

the twenty-second birthday (some states may still use the 18th birthday cutoff). The “functional” definition found in the Developmental Disabilities Assistance and Bill of Rights Act is used by state developmental disabilities planning councils and protection and advocacy agencies (see below) to govern their planning and services. This federal “functional” definition may vary from the definitions used by state agencies. Some states have adopted the federal functional definition, while others use a categorical approach or a variant of both (often limiting the specific conditions which qualify for state-supported services).

However, it is the state definition that determines who is eligible for state supported services and should be used by aging agencies to connect eligible individuals to these services. Since each state’s definition may vary, workers should check with their state’s developmental disabilities agency for the statutory definition that is used to determine eligibility for services in the state. Many states, as part of their general services for people with a developmental disability, also provide supports to older carers. Each state’s legislative mandates differ with regard to the nature and extent of these services, as do their targeting and policies. Again, it is recommended to check with the state developmental disabilities agencies to determine what types of carer support programs they offer, as well as eligibility requirements.

Eligibility for services because of a developmental disability is normally ascertained early in life, since such conditions are generally noted in childhood by school authorities or in the early adult years by vocational rehabilitation agencies. However, among older age adults who may have never been involved with specialty services or who left school at a very young age (some 40 or more years ago), the determination of a developmental disability (as opposed to a psychiatric impairment, functional retardation, age associated decline, or other condition that may impair judgement and performance in daily life) in later life may prove difficult. This may be particularly problematic for aging agencies seeking assistance from public or private developmental disabilities agencies, since no documentation of a lifelong disability may exist. In most circumstances, some background checking to document a lifelong impairment and origin of the condition in childhood may be enough to meet presumptive eligibility requirements of the funding agency.

Estimating the Number of Older Persons with Developmental Disabilities

Informed projections are difficult to make since no specific census data exist on counts of older persons with a developmental disability. However, some estimation processes are available. One is to use the “rule of thumb” of about 4/1000 older persons (age 60 plus). This means that for every one thousand older persons in a geographic area, it is estimated that about four would be older persons with a developmental disability. The 4/1000 estimate offers an outside number of older persons in an area. However, it does not take into consideration adults age 40 to 59 (who often represent from two to three times more individuals—some of whom may evidence premature aging), nor does it provide a way of estimating how many persons may be living on their own, with kin, or in other caring situations. To arrive at an estimate, it is suggested to use the 4/1000 method or confer with your state or local developmental disabilities authorities, obtain their census or registry information, and then add a factor of from two to four times to that number. Either of these methods will provide an outside estimate of the potential number of older persons age 60 plus with a developmental disability in your area that can be used for gross calculations of need.

A more difficult question to answer is how many adults there are with a developmental disability who may still be living with their families? Such estimates are difficult to make, since much depends on historical family decision-making patterns, the availability of independent housing, and the age distribution of older persons with a disability in your region. Dr. Glen Fujiura, a researcher at the University of Illinois at Chicago, estimates that some 1.145 million adults with a developmental disability age 40 and older live with their parents or other kin-related carers aged 60 or older in the United States. Of this number, some 665,000 are adults age 41 to 59 and some 480,000 are adults age 60 plus (Fujiura, 1998).

To arrive at an estimate for your catchment area, first determine the number of adults living in publicly subsidized accommodations or congregate care facilities in your area (such as group homes, apartments, nursing homes, other settings), then deduct these from the estimates you made above. The balance should include the unknowns, most likely persons living with families or own their own. To adjust for age, the following may be helpful: generally, among adults with developmental disabilities living with families, the 35 to 44 age group is twice the size as the 45 to 64 age group, which is ten times the size of the 65 and older age group.

Older Individuals Providing Care and Supports to Persons with Developmental Disabilities

For many years, specialized family support services offered by state developmental disabilities agencies to *older* carers were virtually nonexistent. Most, if any, family support services were targeted toward younger age parents. However, this is now changing as the number of older carers is growing larger each year. This increase in older carers is due to a number of reasons, most of which center around the increasing number of older adults in general (the “baby boomers”) and the increasing number of adults with a developmental disability living at home. In the past few years, there has been a major change in the age composition of our nation’s population because of lower birth rates, increased longevity, and overall improved health status. This same phenomenon is evident among adults with developmental disabilities, many of whom continue to live with their families. Current belief is that most people with a developmental disability will have a life expectancy typical of other people. With recent generations of older people remaining healthier and less impaired longer than past generations, this trend should continue.

We also know that the United States is experiencing a unique phenomenon as the large postwar birth cohort grows older. This “baby boom” generation (persons born between 1946 and 1964) is contributing 50-year-olds to our population at the rate of one person every eight seconds and is thus dramatically changing the age composition of our nation’s population (Kinsella & Velkoff, 2001). This demographic “greying” of America’s population is also affecting people with developmental disabilities. Researchers tell us that many more adults with a lifelong disability are continuing to remain at home. This generation lives with parents in their 60s and older. These older parents represent what is often referred to as the *lost generation* because they make up most of the families who are not generally known to service agencies (Janicki, 1996). As both of these groups become known to local agencies, they add to the numbers of such families of all ages who may need help. Thus, both the growth of the numbers of older adults with a developmental disability and the numbers of carers who themselves are aging are contributing to an increasing interest in this particular subgroup of the American population.

Up until about 25 years ago, many persons with intellectual disabilities were relegated to living their adult lives in large institutional settings. However, much has changed over the past quarter century as federal and state initiatives to enhance opportunities for community living have affected the lifestyle of most of these adults. Dr. David Braddock, formerly at the University of Illinois at Chicago and a highly respected researcher in the area of developmental disabilities, noted in testimony to the Senate's Special Committee on Aging in 2000, that some 1.9 million persons with developmental disabilities are estimated to live at home or with a family carer. Dr. Braddock estimated that some 25% of these carers are age 60 or older. He further noted that a significant portion of in-home supports are being provided by family carers who will be aging beyond the capacity to provide care over the next 10 to 20 years (Braddock, 1998; 1999).

In addition, a growing number of carers will age into eligibility for Older American Act services over the next 10 to 20 years (some estimate that the number will be three times what it is today). Dr. Fujiura, noted above, has estimated that the average age of an adult with a developmental disability living with parents age 60 and older is about 38 years, the average age of an adult living with parents age 41 to 59 is about 22 years, and the average age of a youngster living with parents under age 40 is 14 years (Fujiura, 1998). As can be seen from these age categories, each group of parents will face a variety of challenges. This may be particularly acute for those older parents whose adult offspring are in the 40 to 60 age group, because many adults living with their parents in this age group have Down syndrome, which is associated with premature aging and a high risk for Alzheimer's disease.

In response to these trends, many state developmental disabilities agencies have expanded their support services to include aid to older families. To find out what programs or initiatives are available, contact the state's developmental disabilities agency or its local office or representative.

AN OVERVIEW OF CARE AND SUPPORT ISSUES

The need to provide assistance to older carers of family members with a developmental disability is well documented. For example, researchers at the University at Albany's Center on Excellence in Aging, found that almost 40% of elderly parents, with day-to-day care and oversight responsibilities for adult offspring with a developmental disability, were not generally using day services available from local developmental disabilities agencies. Indeed, most of these families were "hidden" from the formal system. Other studies, such as those conducted by Drs. Marsha Seltzer and Marty Wyngaarden Krauss at the University of Wisconsin and Brandeis University (respectively), have found that these older "perpetual parents" are confronted with many challenges as they continue to provide a home for their son or daughter with a developmental disability (Seltzer, et al, 1994). These studies of older families have noted that there is generally a (1) reluctance on the part of some elderly families to become associated with the formal developmental disabilities system; (2) reticence on the part of some families to even begin to anticipate the inevitability that their son or daughter with a developmental disability will outlive them; (3) strong interdependency between carers and their son or daughter and an inability of elderly carers to reflect upon their own aging and plan for themselves or for their offspring; and (4) lack of coordination between services and the immediate and long term needs of such families.

Such studies have also noted that families with continual caring responsibilities need access to respite and other types of social and community supports. As they grow older, these families not

only experience problems associated with the caring that they have provided all of their lives, but are now also confronted by their own aging and changing life situation. The studies also noted that there is a need: to locate, inform and draw older carers into the aging network; to establish mechanisms to link such carers to family support networks often available through aging, social services or disability agencies; and to provide supports and services that will sustain the carers for as long as possible. The alternative could be a massive failure of caring capacities on the part of older parents and a precipitous demand on out-of-home services for both the carer and those for whom they provide care.

Many of the studies that have been conducted with older families (caring for an adult son or daughter with a developmental disability) suggest that there are “two generation older families” who, with age, become more vulnerable. While some, as Drs. Seltzer and Krauss have observed, are *anticipators* and are either short or long term planners, others are *avoiders*, who put off planning and may find the end of caring disturbing and threatening (Seltzer et al., 1994). For some, this “empty nest” situation is often seen by the mother, in particular, as the end of her central role in life and as something to be avoided. Others may experience some unexpected change in their lives, like the loss of a spouse or a change in living conditions, which may cause them to become overwhelmed and in need. Helping such “two-generation older families” can be highly beneficial to a community. Many older parents or other relative carers have assumed the responsibility of lifetime care for their son, daughter, or other relative, thus bearing the cost of providing a home in the community for their offspring. They are now growing older together and may be in need of help themselves (in addition to help for their adult son or daughter).

Older parents worry about what will happen to their family member if they are no longer capable of caring for him or her, and they identify this concern as an ever-present source of stress and anxiety. Some want to have a plan for the future, but often feel too overwhelmed by their day-to-day responsibilities as carers to focus on the problem. These special needs families often need legal and financial planning assistance to set up viable guardianships and trusts, as well as casework and advocacy to identify, access, and coordinate needed supports and services, now and in the future (Janicki & Ansello, 2000). Obviously, these concerns are experienced even more intensely by aging “perpetual parents” and other aging informal carers. Paradoxically, elderly parents, who are most vulnerable in terms of physical health and fixed financial resources, are typically the very parents who have *not* benefited from recent policies promoting mainstreaming, equal education, supported employment, and independent living options for children and adults with developmental disabilities. These are mostly parents who have had to cope with their adult child being at home for many years, with few services and supports, and who experienced decades of community isolation and “going it alone.” These may also be parents, particularly if they are older, who made active and possibly unpopular decisions to go against medical advice and not institutionalize their young child with a developmental disability and who consequently have never received assistance for their lifelong parenting activities.

What are some of the major concerns of these special needs families? It has been observed (Janicki et al., 1998) that many of these families who care for an adult with a developmental disability have the same needs as other families in caring situations. They want: (1) services that meet their immediate needs (such as, respite, housekeeping assistance, transportation, and emotional supports); (2) help getting financial supports or determinations of eligibility; (3) help obtaining

financial planning information (such as information on entitlements, guardianship and trusts); (4) help negotiating various service systems and advocacy for obtaining services for which they are eligible; (5) assistance obtaining Medicaid and resolving problems with social services agencies; and (6) help making decisions about their lives or the lives of the person for whom they are caring.

Families caring for an adult with a developmental disability do not want or need unnecessary intrusions into their lives. They do not want to feel that someone is coming to talk with them who could eventually disrupt their lives, or possibly take their son or daughter away from them. They do not want to feel threatened or “put upon” and they do not want change imposed on them. Many older families are quite capable of continuing their family responsibilities without special help. However, there are also special needs families whose situation may be such that some help would make their lives that much better. Also, there may be those families in crisis whose situations are quite dire and because help is not available, eventually may face a calamity. Most of all, they want someone who will listen to them and provide help when it is requested.

There are several natural reasons that area agencies on aging should target efforts to help older carers of persons with developmental disabilities (besides the obvious one that under the Older American Act aging agencies have an obligation to aid these special needs families), including the fact that: (1) such older persons, as members of the aging community, are a natural constituency of the aging network and as such have needs that have to be addressed; (2) many of these families or carers have been providing lifelong care for someone with a developmental disability, care that might otherwise have been the responsibility of state or local government agencies (now that they are growing older they need aid with their own lives); and (3) by not helping such parents the problem can eventually become more costly for the community, since emergency or long-term out-of-home care for a person with a developmental disability is expensive, often difficult to find, and requires an investment of considerable staff time for emergency casework.

Who are these Carers?

Usually, one person is responsible for most of the daily care of the person with a disability and for major decisions concerning his or her daily life and activities. In such informal caring situations, this responsibility tends to fall primarily on women. Many older carers are widows and mothers of an adult with a disability and have provided care throughout the life of their adult child. In some households, other family members, such as grandmothers, aunts, wives, sisters and cousins are the primary carers. Fathers, husbands, brothers and nephews are also found as primary carers, but to a lesser extent. Siblings generally have families and jobs of their own and, because of additional caregiving demands, often experience additional stress. During middle age, they must balance their own family and career demands with the care of aging parents and a brother or sister with a disability. They are often expected to assume total responsibility for their sibling after the death of their parents. In some families, this means that a brother or sister will provide care well into their old age and that their children may eventually become involved in caring for them and the person with a disability. In some situations, non-relatives (e.g., a sibling’s former girlfriend, neighbors, and landlord) may also help out.

Grandparents are increasingly serving as the primary carer for one or more of their grandchildren (Heller & Ganguly, 2002; McCallion & Janicki). Some of these children may have a developmental delay or disability. In many instances, the grandparents have assumed responsibility

for care due to the death, incapacitation, incarceration or other non-involvement on the part of their son or daughter, the biological parent of their grandchild or grandchildren. The grandchildren are in most instances minors, but they can also be dependent adults. These adults, for one reason or another, may still be living with their grandparents and expect to be doing so for some time. In such instances, grandparents face special challenges due to vague legal status, having to negotiate new educational, health, or disability-assistance systems on their own, and still contend with the natural parent's involvement (if there is one). In most such situations, the grandparents do this without receiving additional public benefits or financial assistance to help them with these assumed later-life carer duties.

Special Needs of Older Adults with Intellectual and Developmental Disabilities

A number of recently published textbooks have aptly described the special conditions and needs of older adults with developmental disabilities (Janicki & Ansello, 2000; Herr & Weber, 1999). Most of the issues raised focus on adults with intellectual disabilities because of their lifelong limitations in functioning independently within the general society. While many have lived fully integrated and productive lives (even transitioning into the realm of successful aging), others, due to the severity of their intellectual limitations, have lived fairly dependent lives, albeit usually well cared for within their families. As they age, older adults with intellectual and developmental disabilities face many of the same challenges as other aging adults. They experience physical aging and decline, social isolation, disengagement from work or activities, and the challenges of retirement. Yet, they may also face different challenges because they may: have had limited social and vocational experiences; be faced with the loss of their home (with the infirmity or death of their parents or carers) and in need of alternative housing (sometimes precipitously); need help with medical and social resources; and need help accessing senior services or specialty developmental disabilities services.

Some, because of the etiology of their condition, may experience special difficulties as they age (Janicki & Dalton, 1999). For example, adults with Down syndrome, a major cause of intellectual disability, may experience premature aging and may be at high risk for early Alzheimer's dementia as they enter their 40s and 50s. Others, such as adults with cerebral palsy, may experience loss of gross motor functioning earlier than usual, due to a lifetime of challenged muscle use. Premature aging and decline may be specifically problematic since some adults may need services generally provided to older adults who experience decline, yet may not meet the chronological age criteria for admission to these services (a great deal of flexibility may need to be exercised on the part of aging services providers to ensure that their needs will not be deflected due to bureaucratic inertia).

WORKING WITH THE DEVELOPMENTAL DISABILITIES AGENCIES

In contrast to the aging network and its enabling legislation (i.e., the Older Americans Act) and its direct federal oversight by the Administration on Aging, the disability system has a different structure. While there exists a Developmental Disabilities Assistance and Bill of Rights Act and a federal Administration on Developmental Disabilities, these only govern what the state developmental disabilities planning councils, the state developmental disabilities protection and advocacy agencies, and the university-based "centers of excellence in developmental disabilities" do within the state. The *state developmental disabilities planning councils* are responsible for

developing state plans and dispersing federal funds as seed grants, as well as advising the governor and agency administrators on concerns related to the state's activities in the area of developmental disabilities. The *protection and advocacy agencies* look after the rights of people with developmental disabilities, investigate reports of abuse, and generally serve as advocates within the state's legal system. The university-based "*centers of excellence in developmental disabilities*" generally provide clinical and related educational services within cross-disciplinary centers in at least one university per state. There is usually no formal relationship between these federally mandated entities and the state developmental disabilities agencies, with the exception that the state agency head may sit on the developmental disabilities council as one of the federally mandated gubernatorial appointments.

The *state developmental disabilities agencies* are independent of the federal legislation and function under state enabling legislation. These state developmental disabilities agencies (or authorities) are generally responsible for planning, regulating, and funding the service providers who work at the local or regional level to provide services to people (of all ages) with developmental disabilities and their families. In some states, the state developmental disabilities agencies are also providers of services and operate side-by-side with private, not-for-profit agencies (while at the same time overseeing what the private agencies do). Because each state's organizational structure and mandate for services to people with developmental disabilities (including eligibility criteria) differ, it is recommended to check with the state developmental disabilities agency for more information on these aspects.

The state developmental disabilities system is generally made up of the state developmental disabilities agency and a network of private providers or vendors. These providers/vendors may be parent-based voluntary agencies (such as the Arcs), board-based not-for-profit agencies, and quasi-government providers. These community provider agencies generally provide a range of services, including housing (group homes, supportive apartments, independent living aid, etc.), case coordination, adult day care and day activity services, employment and vocational supports, health care and assessments, and a range of other support services.

In general, community provider agencies, the primary deliverer of services to people with developmental disabilities and their families, are usually funded to develop and provide services to address a specific need in the community. As a result, these agencies operate within rules and regulations that specify criteria to the extent of the services, as well as service eligibility, which sometimes means that the agency cannot offer a service to someone in the family who does not meet the eligibility criteria. For example, the staff may address the needs of the person with a disability but not the aging carer or others in the family. Similarly, staff of an aging agency may focus on the needs of the aging carer but not the needs of the person with a disability who is under 60 years of age. Yet the need may be an overall family need. "Agency specificity" may be a significant barrier when the family needs housing or other special help. Many senior housing complexes or assisted living programs do not allow a son or daughter with a disability to live with their parents. Conversely, parents are not permitted to move into group homes for people with developmental disabilities.

Unfortunately, available services do not always meet the immediate needs of a carer or person with disability after help is requested. For example, a family may need respite, but the agency

can only offer assistance with transportation to medical appointments. Another problem may be that each community has a maze of services with specific functions which can be very difficult for families to negotiate. Families seeking help for multiple problems report that they find themselves telling their story and giving the same information over and over again. Such problems may prove to be very frustrating to families not used to working with bureaucracies or multiple service providers. Regrettably, interagency coordination of service provision, for example, among the disabilities, aging, and social services providers, may not always be optimum.

Developmental disabilities agencies are generally found in each community. They may provide a variety of day services, residential programs, individualized supports, and aid to families. They may be governmental or voluntary, not-for-profit agencies. How they are financed and what they do varies from community to community, depending on the organization of each state's developmental disabilities services. In some localities, the service providers or vendors work in concert with a regional or state developmental disabilities agency, which provides their funding. In others, they may be subject to oversight by community boards that set priorities and allocate funding (coming from the state). Some may be involved with planning, but in most instances the planning efforts are not as structured (or mandated) as they are under the Older Americans Act.

Coordination Between the Aging and Disabilities Systems

In many local communities, older adults with disabilities are participating in services provided by the aging network (in most cases, this involves going to their local senior center or nutrition site, or being enrolled in an adult day service program). The Older Americans Act, as amended in 1987, 1992, and 2000 was instrumental in providing legislative support to include older persons with disabilities in the services provided under the Act. Some of the specific requirements of the Act that have helped this cooperation include: (1) encouraging the State Unit on Aging (SUA), Area Agencies on Aging (AAA), and state and local disabilities agencies to cooperatively plan and develop services for older persons with a disability; (2) allowing disabled, dependent adults under the age of 60 to be served at congregate meal sites when accompanying their eligible parent or carer; and (3) authorizing the SUAs and AAAs to target carers who provide uncompensated care for adults with developmental disabilities for special assistance (such as permanency planning, respite, in-home assistance, and other activities). Reauthorizations of the Older Americans Act have also called for establishing a link between the long-term care ombudsman program within the SUA and the protection and advocacy agency within the state and have authorized the Assistant Secretary to explore how senior centers can improve social and physical accessibility of persons with disabilities. However, in reality these provisions have rarely been carried out.

In addition to the Older Americans Act, the other legislation affecting the participation of older people with disabilities in aging network programs is the Americans with Disabilities Act (ADA). Title II of the Act prohibits discrimination in the provision of state and local government services for qualified people with disabilities. Title III bans discrimination in public accommodations, such as senior citizen centers, adult day program sites and social services centers (Janicki, 1991; 1993). Under the ADA, reasonable modifications must be made to policies, practices or procedures to avoid discrimination. Auxiliary aids and services must be provided to ensure effective communication, and physical barriers must be removed if readily achievable. These accommodations are not required if they would fundamentally alter the nature of the goods or

services or would result in undue burden to the public entity. These mandates should provide considerable support for linking the aging and disability networks.

STATE INITIATIVES ON PARTNERING WITH DEVELOPMENTAL DISABILITIES AGENCIES

Partnership initiatives between the aging and developmental disabilities state agencies can help implement regional or local disability-related activities under the National Family Caregiver Support Program. Developing such partnerships can involve a number of approaches, including developing and maintaining interagency agreements, spearheading local networks, sharing staff, common planning, issuing directives on cooperation and resource allocation, interagency cooperation with budgetary submissions and allocations and regulatory reviews, and discussions among gubernatorial cabinet members (in particular the heads of the aging and developmental disabilities agencies).

Much like the effort tried in 1987 at the first Wingspread Conference on Aging and Developmental Disabilities, where state administrators of aging and developmental disabilities agencies were brought together for common dialogues, each state has the opportunity to have the senior officials of state agencies on aging and developmental disabilities open a dialogue on a common issue (Ansello & Rose, 1989). The National Family Caregiver Support Program offers an excellent opportunity for such dialogue as the issues and needs of family carers of persons with developmental disabilities cross the orbit and boundaries of the aging agencies. Dialogues across these two systems are almost mandatory if state implementation of this program is to be successful. Noted below are two ways of beginning interagency activities with respect to this new program.

Interagency Agreements and Formal Relationships

The purpose of an interagency agreement is to bind two or more agencies to a common purpose and to clearly delineate the roles and responsibilities of each. Interagency/intergovernmental state/local agreements can be useful defining activities and identifying a common goal. Such agreements may be general agreements or related to one or more specific areas of coordination. For example, a *general agreement* may address any or all of the following actions: encourage staff of each agency to consult and to share expertise, creatively solve common problems, and advocate for services; plan and implement appropriate models or demonstration programs; exchange information and data; use cooperative funding opportunities available from federal agencies and private organizations; plan for future needs; identify current gaps in services; develop joint annual workplans; consult on development of state or local plans; encourage cooperation and coordination of services between regional/local aging and developmental disabilities agencies; and coordinate public education and awareness campaigns.

Specific agreements may also be set up for a particular purpose, such as implementing the NFCSP and related activities. These may call for joint planning, sharing staff or other resources, dialoguing about eligibility and referrals, and agreeing on other areas of common interest. Such interagency agreements may also have broader uses such as: being helpful in developing guidelines for senior program requirements and regulations; developing guidelines for pre-service and in-service training and education programs in aging with application to disabilities; adopting an agreed-upon, standardized system of data gathering and bookkeeping; developing and delivering joint

testimony before legislative or budget bodies or committees; and making recommendations for legislative action. Such agreements may be implemented at the state, regional and local levels. One such agreement on the federal level that has been signed and implemented is between the Administration of Developmental Disabilities and the Administration on Aging. In addition, there are examples of such agreements in a number of states.

Partnership Initiatives by State Agencies

Developing partnerships can involve a number of approaches, including bringing the aging and developmental disabilities agencies together, organizing the community, and mandating interagency approaches. Using an interagency task force is a helpful initial approach (Janicki, 1992).

The SUA can reach out to the state developmental disabilities agency and establish an interagency task group that would be charged with coordinating planning, training and services development. Techniques that bring state officials together can include: inviting comparative level administrators from the aging and developmental disabilities to speak to a provider/consumer group or at an interagency conference; inviting representatives of aging and developmental disabilities to be on a planning committee for a conference or task group on aging and disabilities; working toward formalizing a relationship between the aging service agencies, developmental disabilities agencies, and the state's developmental disabilities planning council through mutually agreed upon roles and responsibilities that stem from an interagency memorandum of understanding; and working toward establishing an interagency task group that examines a particular long term care problem (e.g., housing, adult day services, family assistance) that involves both dependent elderly and older disabled populations.

State Direction for Local Activities

One administrative question to consider is whether the state's effort to implement the NFCSP will be a top-down or a bottom-up approach. If it is to be a top-down approach, then the methods noted above would be applicable, but if it is to be a bottom-up approach, then the methods noted below would be more applicable. Top-down approaches generally mean that the state and state-level groups participate in establishing policy and methods for implementation. With regard to the NFCSP, it may mean that the SUA, working with the state developmental disabilities agency and (potentially) the state's AAA association and consumer organizations, may design a method for successful implementation of the NFCSP in the state. This would then be shared with local organizations and supported by the state. Bottom-up approaches may take on a variety of methods, but generally the implementation is left to the local organization and is supported as it carries out the responsibility for implementation in the best way it sees. This may involve doing it within the agency, networking with other agencies or providers, or assigning this responsibility to one or more providers within its jurisdiction. While not truly bottom-up (since the local implementation may not percolate to affect the state), the responsibility for implementation rests at the local level and the implementation method may eventually affect state policy. The state agency's position in such situations may be completely "hands-off" or it may "work behind the scene" and guide the local effort to ensure that it is carried out successfully within select parameters.

UNDERTAKING A LOCAL NFCSP INITIATIVE

To begin a local NFCSP initiative directed toward older carers of persons with a developmental disability, useful strategies are to decide how to approach the initiative, determine the scope of the population of families potentially in need, and define how to implement the organization of the initiative. Discussed below are some strategies for deciding how to approach such an initiative.

One of the first things to undertake is to identify the scope of the problem in your community. It is helpful to determine how many such families in need are in the community. If you do not have access to a state registry or census data on people with disabilities and their families, then first identify assumptions which will guide your estimation of the number of such families (see earlier discussion on estimating the number of persons with developmental disabilities). Once you define your assumptions on estimating how many families may be in need and determine a workable number, consider the following: (1) what are their needs and which needs are most immediate? (2) what resources currently exist in your community to help these families? (3) what are the disability and social services networks doing to help such families and carers? (4) what would happen if you did nothing to help them? and (5) what do you want to do?

To capture the needed information, it is useful to either formally survey your locality and its agencies (a mail questionnaire can help here) or informally secure the information through meetings or networking processes. Certainly, asking other agencies in the disability, social services and health care system to inform you of their activities, services, and eligibility criteria can be a helpful step. Assessing the impact of an initiative is something that may be done within the agency or in consultation with other agencies. Finally, an administrative decision needs to be made as to how to proceed.

Organizing the Initiative

There are a number of ways to organize a community-based carer assistance initiative targeting older carers under the National Family Caregiver Support Program (NFCSP), including organizing a network, developing and building a coalition, and working on interagency committees or task forces. All of these activities assume that the agency will want to work in concert with other providers or organizations involved with families or people with developmental disabilities. It is also assumed that the agency is interested in developing long-term capacity and a willingness to develop a structure that will exist for many years. Thus, this paper assumes that capacity building, partnering, and a commitment to long term investment are the administrative underpinnings of the aging network's efforts with undertaking an initiative responding to the NFCSP. The assumption is also made that an AAA may wish to invest some effort in making its NFCSP initiative a permanent fixture, and thus, may wish to organize its activities in a manner so as to include a more comprehensive approach to community resource development.

Taking the Lead

In some localities, one network (that is, aging or developmental disabilities) may be more developed or prominent than the other. A key question is which network would be best suited to take the initiative to develop a local program that will reach out and help older carers? Obviously, arguments can be made for either or both systems to take on this responsibility. The main question is, should the aging agency take the lead? It may be argued that when it comes to reaching out and helping older families, AAAs are better prepared to do outreach because they: (1) have more of a focus on family issues; (2) have more information and resources related to issues for older people; and (3) provide more generic aging services, which may result in their outreach being more effective. The reality is also that the NFCSP calls upon AAAs to carry out carer assistance. However, nothing prevents them from working out relationships with other providers to undertake the main parts of the initiative; for this reason, the following information is included.

It may be argued that aging agencies have a more neutral status in their community, thus older families may perceive less of a stigma attached to getting aid from an aging agency. There is also the belief that many older and potentially vulnerable families will be less fearful that their child or relative may be taken away by an aging agency. In addition, aging agencies may be better positioned to help, because many carers need aging related services. Some may believe that disability agencies often do not understand what aging agencies do and what aging related services may be available. Some think that disability agencies are more likely to hold a “dysfunctional perspective” of families, and because they are concentrating on the needs of the adult with a developmental disability, may not be sympathetic to the needs of older carers. For all of these reasons, many believe that the aging agencies are the best suited and positioned to undertake a NFCSP initiative.

Alternatively, some believe that when it comes to finding people with a developmental disability and their families, local developmental disability agencies may be better prepared because they: (1) focus more on the individual needs of the person with a lifelong disability; (2) have more information and resources related to lifelong caring issues; and (3) know how to work with people with special needs and disabilities. Some also believe that developmental disability agencies are in a better position to aid families and other carers because the purpose is to address the needs of someone with a developmental disability. For example, disability agencies: (1) are better at diagnostic and behavioral intervention issues; (2) know disability issues and are tied to rehabilitation systems; and (3) are familiar with the barriers that families face when they have a member with a disability. Also, some believe that aging agencies do not understand what disability agencies do and what disability related services may be available. In addition, aging agencies may have difficulty determining eligibility for disability services and having these determinations accepted.

As the merits of working through either aging or disability agencies are being weighed, one consideration is who is most capable of undertaking and following-through on this type of effort. The following questions can help guide this decision-making process: (1) who has the best outreach program? (2) who has the best support system? (3) who has the best history of networking and working with your locality's agencies? (4) who is perceived most favorably by families in your community? (5) who is willing to do it? and (6) who is capable of sustaining this level of effort?

It is evident from the above that the mandate under the NFCSP can stimulate the development of partnership arrangements among the aging agencies, disability agencies and other social service or health agencies when it comes to targeting older informal carers of a person with a lifelong disability. Such an opportunity can lead to many benefits, including instigating or renewing interagency agreements and working relationships, sharing resources, staff exchanges, and provision of non-duplicative services (whether outreach, casework, information and referral, direct supports or some other needed service).

Approaches to Building Community Support

Building local support for an agency or agencies to undertake a NFCSP initiative can be undertaken by a variety of approaches, including networking, coalition building, and developing local task forces.

Networking. Networking is an informal means of connecting with people or agencies with similar interests or agenda. It means talking with colleagues and other people inside and outside of your discipline or interests and linking these persons with each other. Networking can help in: (1) identifying a critical mass of interest; (2) building a constituency that will be able to lend support, influence and help when necessary; (3) opening “the door to opportunity;” and (4) generating activity and results. When beginning a networking effort, it is helpful to first identify a core group of people who share your agency’s interest in developing a carer assistance initiative. The group should include people from the aging network, people from the developmental disabilities network, and family carers. Once this is done, the next step can be getting together and meeting informally as a small group and then, later, expanding the group by bringing in others who can help with identifying solutions and next steps. At this stage, consider involving persons in the health and social services arena and identifying one person who will be the lead for moving the effort along.

Once established, continue to problem solve and to bring in people who can help with overcoming any barriers you may encounter. Draw in key officials from the developmental disabilities, aging, social services, health and community supports networks. One way to formalize a network is to call a larger group meeting to promote a dialogue among networks, which can also be used to chart future directions. This can be done by agreeing to: (1) share information on what each is doing; (2) exchange referrals; and (3) form a coalition that would work toward furthering a specific goal (for example, advocating for one of the local government agencies to develop a carer assistance program, agreeing to establish a local coalition, or setting up a clearinghouse for information exchange).

Coalition Building. A coalition is an alliance of persons, agencies and/or organizations coming together for some joint action toward a common goal, with identifiable outcomes and specific tasks defined to achieve the outcomes. Coalition building differs from networking in several key ways: it is more formalized, key participants may be specifically named or assigned, and it is generally identified with a specific function. Coalition members should include agency or service networks that are affected by the problem or have the resources to address the goal. The aging network should consider including representatives from the aging and developmental disabilities services such as hospitals and health agencies, social service agencies, mental health programs, local and regional Alzheimer’s chapters, public and private agencies, local aging agencies, adult day services programs, and local disability agencies, as well as city, town, and county government

officials. A balance of providers, decision-makers, and key advocates should be invited to join. Coalition building works best when one person (a “spark”) becomes identified with the effort and has a vision of where things should go. Further, within the coalition, subcommittees can be formed around tasks and assigned responsibility for task completion.

Using existing coalitions or structures is sometimes more productive than forming a new coalition. There may already be a coalition in your community made up of human service agencies and organizations. By tapping into an existing aging, disabilities or community service coalition, it is possible to amplify your effort in establishing a family carer support program. Another way of getting this program invested in the greater community is to form a carer-oriented task force as part of some larger committee. Look for a committee already in place, possibly under the formal auspice of the AAA, a local government mental health or developmental disabilities department, a university center on aging or disabilities, a foundation, a community planning body or interagency council, or a health systems agency or similar planning group. As a carer task force, such a committee has the advantage of being in the official loop. This eases the task of sharing information, tapping resources, and building the support needed for a program in the community.

Setting up a Local Carer Assistance Task Force. Networking and networking meetings made up of people from both the aging and developmental disabilities systems can set the stage for building the relationships needed to develop a workgroup, committee or task force that can be officially charged to help organize, coordinate, oversee, or simply advise a NFCSP initiative. The development of such formal committees or task forces can be a precursor to other activities when you are in a highly urbanized metropolitan area. Highly urbanized areas, with a complexity of staff interactions, agency territories, and disparate funding and oversight sources, often need a more structured brokering approach. Rural areas, composed of few agencies and interested or affected staffers, can often come to cooperative decision-making over a meal at a local restaurant. Formal task forces are generally set up to achieve a specific aim—such as new program development, interagency cohesion, or promotion of accessibility. To get such an effort off the ground, it is useful to have a formal auspice—that is, the sanction and support of a formative group whose reputation and role are such that it will draw participants to the task force. In this case, the charge should come from the SUA or from an AAA.

Developing Local Aging and Developmental Disabilities Networks. One side benefit of setting up a NFCSP initiative is that any network or task group set up in the locality may (or will), by virtue of its membership and discussion, broaden its interest into a discussion of a range of issues affecting older people with developmental disabilities. Thus, one goal may be to help foster a local network to promote community integration (that is, greater use and inclusion of people with lifelong disabilities within the overall fabric of the community, including more use of aging network programs, such as senior centers and nutrition sites). In this regard, a newly organized network group or coalition can be the driving force behind fostering greater integration and inclusion. In many communities, networking groups or coalitions have lead to, or have been formed from, task forces of agencies/providers in either the developmental disabilities system or the aging network.

CARRYING OUT AN NFCSP INITIATIVE

To implement a National Family Caregiver Support Program initiative within an aging agency, it is useful to define the issues and needs facing parents who are older carers of people with

a developmental disability. At this point, internal discussions need to take place to determine “who,” “what,” and “where.” This means that preliminary activities, such as fact finding, local assessment, and planning have already been done and the information gleaned can now provide the support for instituting such an initiative. Administrative approval within the aging agency is now needed to get the initiative started. Once the “go-ahead” has been given, work on the details and implementation should begin. What follows are some things to consider before proceeding.

Congress has acknowledged that helping carers in general is a significant need in our communities. It has also determined that helping older families caring for someone with a developmental disability at home, the “perpetual parents,” is one facet of that need. Thus, it should be assumed that, given the demographics of the United States, this is a significant problem and the response should not be a one-shot effort, particularly with the projection of increasing numbers of persons in home care in the years to come. There should be a multi-year commitment to the initiative and it should be designed to reduce service duplications and promote service integration. It should be organized as a community response calling upon a variety of providers to aid and collaborate. Once there is institutional commitment, the first major decision to be made is whether to undertake this type of initiative within your agency or contract it out. This decision may be governed by whether your agency does direct work, normally contracts out, or works through other agencies.

If you have discretion in making this type of decision, ask the following questions: how would families respond to outreach or other contacts from your agency? How would families respond to outreach or other contacts from a disability agency? An aging agency? Another agency? What are your agency’s policies about contracting out or doing things in-house? What are the capabilities of external agencies or internal branches of your own agency? If your agency takes this on, who will get the assignment? First, it is important to explore what to consider if the decision is made to contract out.

Contracting Out. If the decision is that you want to have this project done outside of your agency, then the first question is who should do it. Consider that whoever does it needs to understand the aging and disability systems, as well as the dynamics, character, and needs of the target families. Sometimes you may have the flexibility to approach any agency you want and other times you may be restricted by your organization's or government's policies on contracting out, such as prior approval, a competitive request for proposal (RFP) process, or other contract award procedures that have to be followed. If you are restricted to having to bid out the contract, be sure to carefully craft your award notice so as to attract the best agencies or providers. If you have wider discretion as to how to handle the selection process, consider some of the following questions in choosing an agency or provider to do this project: Who has the best outreach program? Who has the best support system? Who has the staff that can relate to these families? Who has the best history of networking and working with agencies? and Who is willing to do it?

Similar questions can be woven into the review criteria for a RFP (Request for Proposals). When choosing an outside agency, consider whether they have a *family focus*, which is needed because a *disability* or *aging* focus is not sufficient. For all agencies that express an interest in doing the project, consider whether they can do a quality job with the funds you have allocated? Will they be able to stay with the families for as long as needed? Do they have the means to provide oversight and supervision? If not, who will do it? Will they address the immediate problem (that is stabilize

the family in crisis or need) or create a demand for new or extensive services that cannot be met? What funds will be used for the services that the agency identifies as needed by the families? As you proceed, there may be other considerations in choosing and overseeing the contract agency, which you can handle as you would any other contract situation.

Doing it Within. If your agency is undertaking this initiative internally, then you need to decide who inside the organization will be given this responsibility. If your agency is small, this may not be a major issue. You may take on the responsibility yourself or you may hire someone to do it. If you work for a large agency, with separate divisions or units, the decision of who will do it may not be as easy. Consider the following: which agency function or branch should do this (that is, to what part of the organization does this get assigned)? How do you allocate the project components (that is, outreach, information and referral, training and education, and casework, advocacy and brokering) and how will these be coordinated? Will they be under one branch of the agency or spread over several? Which agency function or branch will get the information out to the community and then do the follow-up? How does the public get informed—that is, how do you set up external notices and information on who to contact at your agency?

As noted above, instituting a NFCSP initiative to aid families with a member who has a developmental disability can be a simple or complex operation, depending on a number of factors, including how much you want to invest in this effort. However, to make it successful and keep it low-cost, it is helpful to include community development activities such as: building off natural networks to get started; developing a coalition; letting people in the disability system know about your project; recognizing that there will be "turf" issues among the agencies in your or other networks and developing strategies to address them; reviewing the pros and cons of organizing your community or attempting to build relationships across agencies; and getting representatives of families involved in the process. Deciding who can best achieve these activities is an important criterion for selecting where in your agency to place the initiative.

Getting Support. Once the decision has been made as to how to proceed, remember that you may need to get the community's disability agencies to be part of the effort. To do this, it might be best to hold some face-to-face meetings with the disability system people and review approaches to building community support as described earlier. First, you need to decipher what constitutes the disability system: who are the key players? Where is it located? What does it do? What is its language? What are its funding streams? Unless you are already intimately involved with this system, you will need to find out what this system is like. You need to find out where the "power centers" are and who the "key actors" are. One area of concern that may emerge is "what are you doing in my territory," or the familiar "turf issue" seen in many communities.

It will move the process along if you explain how the Older Americans Act functions and the mandate under the National Family Caregiver Support Program. Through this explanation you can let them know what your agency plans to do and the limit of your activities. Leave them with three clear messages: (1) you are not their competitor, (2) you are not trying to give them more work, and (3) you are willing to share resources. The second set of activities will involve getting your message out to the greater community. The general community needs to know what you are doing. Approach this by providing as much information as you can.

Sharing Resources. One issue that often comes up with AAAs is how to allocate scarce resources to additional mandates or initiatives. Although the National Family Caregiver Support Act provided the mandate for helping older families caring for people with developmental disabilities, no specific funds have been allocated beyond the general funds assigned to this Program. Thus, AAAs may be forced into a quandary wanting to comply with the law and institute outreach and casework for these families, but not having additional resources to do a complete job. One solution to this dilemma is open discussion with state and local developmental disabilities agencies to garner both staff and fiscal supports that can be allocated to the initiative or used once a family has been identified and referred into the system. While not always guaranteed to be fruitful, this approach has been successful in some areas and can be a source of additional resources and supports for AAA efforts to implement these disability-specific provisions of the NFCSP.

SOME FINAL CONSIDERATIONS

Working within the greater disability system to build the NFCSP initiative will prove to be more productive than attempting to do it in isolation for several reasons: (1) drawing in the disability providers will provide for a valuable set of resources that can be called upon when the family or an individual within the family needs assistance; (2) sharing of scarce financial resources can help stretch the available funds under the NFCSP so as to optimize outreach and assistance efforts; (3) many of the families that are found or contacted may already be in touch with other networks and collaboration will negate duplication of effort or waste of scarce resources; and (4) institutionalizing help for older carers within the community's planning and resource allocations structure will call for cooperation and collaboration.

Author Description and Acknowledgments

Matthew P. Janicki, Ph.D. is research associate professor of human development at the Institute of Disability and Human Development at the University of Illinois at Chicago, and serves as director for technical assistance for the Rehabilitation Research and Training Center in Aging with Mental Retardation at the University. He is also research professor and co-director for the Center on Intellectual Disabilities at the University at Albany (New York). Formerly, he was director for aging and special populations for the New York State Office of Mental Retardation and Developmental Disabilities.

Dr. Janicki was a Joseph P. Kennedy, Jr. Foundation's Public Policy Leadership Fellow, spending a sabbatical year at the National Institute on Aging and the United States Senate. He is the author of numerous books and articles in the area of aging, dementia, public policy, and rehabilitation with regard to people with intellectual and developmental disabilities and has lectured and provided training in aging and intellectual disabilities across the world. Dr. Janicki was the chair of the United States International Council on Mental Retardation and Developmental Disabilities and currently is the chair of the aging special interest research group of the International Association for the Scientific Study of Intellectual Disabilities.

He was the principal investigator for "Supporting Caregivers: A Demonstration of Linkages to Help Older Caregivers of Family Members with a Developmental Disability," a multi-year grant project funded by the Administration on Aging between 1993 and 1996. The project was directed toward model development, training, and dissemination to facilitate area agency on aging outreach and services to carers of older adults with a developmental disability. He was also a co-investigator on a project examining the needs of grandparents who are primary carers of children and adults with developmental delay or disabilities and the project director of an effort to provide the World Health Organization with a series of background reports on promoting longevity among adults with intellectual disabilities throughout the world. He is currently the principal investigator of a NIDRR-funded project examining how community agencies are providing community supports to adults with intellectual disabilities affected by Alzheimer's disease and the co-principal investigator on a new project funded by the Administration on Aging to The Arc of the US which is providing training and technical assistance to state and local aging agencies in supporting older parents and other carers of adults with intellectual and developmental disabilities who live at home.

REFERENCES

- Ansello, E.F., & Rose, T. (1989). *Aging and Lifelong Disability - Partnership for the Twenty-First Century* (The Wingspread Conference Report). Palm Springs, CA: Elvirita Lewis Foundation.
- Braddock, D. (1998). Aging and developmental disabilities: demographic and policy issues affecting American families. Statement before the Senate Special Committee on Aging Forum "Can we rest in peace? The anxiety of elderly parents caring for baby boomers with disabilities." September 18, 1998.
- Braddock, D. (1999). Aging and developmental disabilities: demographic and policy issues affecting American families. *Mental Retardation*, 37, 155-161.
- Fujiura, G.T. (1998). Demography of family households. *American Journal of Mental Retardation*, 103, 225-235.
- Heller, T., & Ganguly, R. (2002). Grandparents raising grandchildren with disabilities. Report issued by the University of Illinois at Chicago's Rehabilitation Research and Training Center.
- Herr, S. & Weber, G. (1999). *Aging, Rights and Quality of Life: Prospects for Older People with Developmental Disabilities* (392pp.). Baltimore: Paul H. Brookes
- Janicki, M.P. & Dalton, A.J. (Eds.). (1999). *Dementia, Aging, and Intellectual Disabilities: A Handbook* (488pp). Philadelphia: Brunner-Mazel.
- Janicki, M.P. & Ansello, E. (Eds.). (2000). *Community Supports for Older Adults with Lifelong Disabilities* (585pp). Baltimore: Paul H. Brookes.
- Janicki, M.P. (1991; 1993) *Building the Future: Planning and Community Development in Aging and Developmental Disabilities*. Albany: New York State Office of Mental Retardation and Developmental Disabilities.
- Janicki, M.P. (1992) *Integration Experiences Casebook: Program Ideas in Aging and Developmental Disabilities*. Albany: New York State Office of Mental Retardation and Developmental Disabilities.
- Janicki, M.P. (1996). *Help for Carers for Older People Caring for an Adult with a Developmental Disability*. Albany: New York Developmental Disabilities Planning Council.
- Janicki, McCallion, Force, Bishop & Lepore; (1998). Area agency on aging outreach and assistance for households with older caregivers of an adult with a developmental disability. *Journal of Aging & Social Policy*, 10(1), 13-36.

- Kinsella, K., & Velkoff, V.A. (2001). *An Aging World*. U.S. Census Bureau, Series P95/01-1. Washington, DC: U.S. Government Printing Office.
- McCallion, P., & Janicki, M.P. (Eds.). *Grandparents as Carers of Children with Disabilities - Facing the Challenges*. New York: Haworth Press.
- Seltzer, M.M., Krauss, M.W. & Janicki, M.P. (Eds.). (1994). *Life Course Perspectives on Adulthood and Old Age* (229pp). Washington: AAMR.